

The background of the entire page is a close-up, artistic photograph of red blood cells. The cells are shown in various stages of focus, with some appearing sharp and others blurred, creating a sense of depth. The color is a vibrant, slightly dark red.

The Facts on von Willebrand Disease

Bleeding disorders affect more than three million people in the United States. The most common inherited bleeding disorder is von Willebrand disease (VWD). Named for Erik von Willebrand, a Finnish doctor who first described the condition in 1926, VWD affects your blood's ability to clot and can lead to heavy, hard-to-stop bleeding. In rare cases, the bleeding can damage internal organs or even be life threatening.

What is VWD?

With VWD, you either have low levels of a certain protein in your blood, or the protein doesn't work the way it should. The protein is called von Willebrand factor. It is made in the walls of your blood vessels and released into your blood.

Normally, when one of your blood vessels is injured, a hole forms and you start to bleed. As soon as this happens, small cells in your blood called platelets clump together to plug the hole in the blood vessel and stop the bleeding. Von Willebrand factor acts like glue to help the platelets stick together and form a blood clot.

Von Willebrand factor also carries with it clotting factor VIII (8), another important protein that helps your blood clot. Factor VIII is the protein that is inactive or missing in [hemophilia](#), another clotting disorder.

VWD is a lifelong disorder; there is no cure. However, most people have a mild form that causes little or no change in their lives. Even those with more severe forms of the disease can live normal, active lives with early diagnosis and the right treatment.

How common is VWD?

VWD occurs in about 1 out of 100 people and in men and women equally. However, women are more likely to notice the symptoms because of heavy or abnormal bleeding during their menstrual cycle and after childbirth. VWD is the most common bleeding disorder affecting women.

There are three major types of VWD:

- **Type 1 VWD** causes a low level of the von Willebrand factor and may cause lower levels of factor VIII than normal. This is the mildest and most common form, accounting for 3 out of 4 people with VWD.
- **Type 2 VWD** causes the von Willebrand factor to not work the way it should, even though the body makes normal amounts of it. Type 2 VWD is divided into subtypes 2A, 2B, 2M, and 2N. Each type is caused by different gene mutations and treated differently. The treatment you receive for type 2 VWD varies according to your subtype, so knowing the exact type you have is important.
- **Type 3 VWD** usually causes you to have no von Willebrand factor and low levels of factor VIII. Type 3 is the most serious form of VWD, but it is very rare.



What causes VWD?

VWD is almost always inherited. Your parents pass the gene for the disease on to you. You can develop types 1 or 2 VWD when only one of your parents carries the gene for it. You usually inherit type 3 VWD only if both of your parents pass the gene on to you. Your symptoms may be different from your parents' symptoms.

Some people develop a form of the disease later in life as a result of other medical conditions. This is called acquired von Willebrand syndrome.

What are the signs and symptoms of VWD?

Signs and symptoms depend on the type and severity of the disease. Many people have such mild symptoms that they may not know they have the disorder. Some people have the gene for the disease but don't have any symptoms.

If you have type 1 or type 2 VWD, you may have the following mild to moderate symptoms:

- Frequent large bruises from minor bumps or injuries
- Frequent or difficult-to-stop nosebleeds
- Extended bleeding from the gums after a dental procedure
- Heavy or extended menstrual bleeding in women*
- Blood in your stools from bleeding in your intestines or stomach
- Blood in your urine from bleeding in your kidneys or bladder
- Heavy bleeding after a cut or other accident
- Heavy bleeding after surgery

*Heavy menstrual bleeding is the most common symptom in women. If it isn't treated, it can lead to iron deficiency and anemia. (Not all heavy menstrual bleeding is due to VWD.)

If you have type 3 VWD, you may have any or all of the type 1 or type 2 symptoms, as well as:

- Severe bleeding episodes for no reason. These bleeding episodes can be life threatening if not treated right away.
- Bleeding into soft tissue or joints, causing severe pain and swelling.

How is VWD diagnosed?

VWD is sometimes difficult to diagnose. People with type 1 or type 2 VWD may not have major bleeding problems. As a result, they may not be diagnosed until they have heavy bleeding after surgery or some other trauma.

On the other hand, type 3 VWD can cause major bleeding problems during infancy and childhood. As a result, children with type 3 VWD are usually diagnosed during their first year of life.

To find out if you have VWD, your healthcare provider will:

- Take a complete personal and family medical history.
- Do a physical exam to look for unusual bruising or other signs of recent bleeding, as well as evidence of liver disease or anemia.
- Order blood tests that will check how quickly your blood clots and the levels of clotting factors in your blood.

Your healthcare provider may also refer you to a hematologist (a doctor who specializes in treating blood diseases) to confirm the diagnosis and provide follow-up care.

Early diagnosis is important to make sure you are treated effectively and can live a normal, active life.

How is VWD treated?

Your healthcare provider will decide what treatment you need based on the type of VWD you have and how severe it is. Most cases are mild, and you may



need treatment only if you have surgery, a tooth extraction, or an accident.

Treatments for VWD include medicines to:

- Increase release of von Willebrand factor and factor VIII into the bloodstream.
- Replace von Willebrand factor.
- Prevent breakdown of clots.
- Control heavy menstrual bleeding.

What are tips for living with VWD?

If you are diagnosed with VWD, it is important that you:

- Follow your treatment plan as directed by your doctor to prevent complications.
- Receive routine follow-up care. How often you see your doctor will depend on the severity of your bleeding disorder, your symptoms, and which treatments you are using.
- Maintain a heart-healthy lifestyle.
- Talk with your doctor about how to prevent or treat complications.

How do you stay safe living with a bleeding disorder?

- Talk to your doctors, dentists, employers, loved ones, and others about your bleeding disorder and what to do in case of emergency.
- Talk to your doctor about preparing for surgery, as well as the potential risks and complications.
- Talk to your doctor or pharmacist about which medicines are safe for you to take. Some medicines, such as aspirin or other pain relievers, increase the risk of bleeding.

Children and women may have additional tips they should follow. Talk with your or your child's healthcare provider for more tips for living with VWD.



Learn more

Visit www.nhlbi.nih.gov/health/bleeding-disorders to learn more about VWD and other rare bleeding disorders.

